



Consultation response form

National Data Guardian for Health and Social Care

About you

You do not have to tell us this information if you do not want to.

Please fill in and/or tick the appropriate response.

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Freedom of Information

Information provided in response to this consultation, including personal information, may be published or disclosed in accordance with the access to information regimes. The relevant legislation in this context is the Freedom of Information Act 2000 (FOIA) and the Data Protection Act 1998 (DPA).

If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals amongst other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality

disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.

The Department will process your personal data in accordance with the DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties. However, the information you send us may need to be passed on to colleagues within the UK Health Departments and/or published in a summary of responses to this consultation.

I do not wish my response to be published in a summary of responses ☐

Are you responding (please select one):

As a member of the public ☒

As a health or social care professional ☐

On behalf of an organisation ☐

If you are responding as an individual, what is your gender?

N/A

If you are responding as an individual, what is your age?

N/A

If you are responding as an individual, what is your ethnic group?

Choose one option that best describes your ethnic group or background

White ☐

Mixed/Multiple ethnic groups ☐

Asian/Asian British ☐

Black/African/Caribbean/Black British ☐

Chinese ☐

Arab ☐

Other ethnic group ☐

If you are responding as a member of the public, please supply the following details:

Are you

A patient or service user with a long-term condition or disability ☐

A carer or family member ☐

An interested member of the public ☐

A retired health or social care professional ☐

Other (please give details)



A group of patients and members of the public with an interest in research using health data, allied to the Health eResearch Centre. Member of the Farr Institute.

If you are responding as a health or social care professional, please supply the following details:

Area of work

- | | |
|-----------------------------|--------------------------|
| NHS | <input type="checkbox"/> |
| Social Care | <input type="checkbox"/> |
| Private Health | <input type="checkbox"/> |
| Voluntary | <input type="checkbox"/> |
| Regulatory Body | <input type="checkbox"/> |
| Professional Body | <input type="checkbox"/> |
| Education | <input type="checkbox"/> |
| Union | <input type="checkbox"/> |
| Local Authority | <input type="checkbox"/> |
| Trade Body | <input type="checkbox"/> |
| Other (please give details) | <input type="checkbox"/> |

If you are responding on behalf of an organisation, please supply details:

As above. See www.herc.ac.uk/ppie for further details.

Consultation Questions

1) The Government proposes that: the remit of the National Data Guardian for Health and Social Care role should follow the health and care data.

The H@PPI Forum strongly support the establishment of the National Data Guardian and agree that the role should 'follow the health and care data', extending controls where needed, rather than just organisations within the health sector. Nonetheless, this is a broad statement and will require clarification in due course to determine exactly what it means.

2) The Government is seeking your views on: what are the key factors and issues that need to be considered when determining whether children's social care should be part of the National Data Guardian remit and where the National Data Guardian could make a positive contribution to care services for children and young people?

We do not feel we have the expertise to comment on this.

3) The Government proposes that: the National Data Guardian should be able to provide advice to all organisations that hold health and care data which could be used to identify individuals.

We support this proposal and propose that this should be an essential part of the National Data Guardian's role: thus, it is a case of 'must' rather than 'should'.

This proposal applies to 'data that could be used to identify individuals', however it is unclear how this criterion will be assessed and therefore, to which data this will (and will not) apply. Furthermore, the Government should consider whether there are cases where the National Data Guardian may provide advice to individuals, rather than only organisations.

4) The Government proposes that: any regulators with a responsibility for overseeing organisations which routinely hold, use and share health and care data, should consult the National Data Guardian on the criteria they use to assess an organisation's use of data.

We are in agreement, but wish to highlight that the role should not be implemented in such a way that it becomes an excessive burden and/or an obstruction to effective data sharing.

5) The Government proposes that: organisations holding health and care data which could be used to identify individuals should be required to publish all materials demonstrating how they have responded to advice from the National Data Guardian.

We agree with this proposal.

6) The Government proposes that: the National Data Guardian should be required to publish an annual report which should include a report of all the advice provided in the relevant year and an overview of how the relevant organisations responded to it.

We agree with this proposal.

7) The Government proposes that: the referral role of the National Data Guardian with the CQC and ICO should be set out in a Memorandum of Understanding.

We agree with this proposal. However, who will oversee this relationship and ensure effective liaising and management of referrals between these organisations? Moreover, who will oversee the National Data Guardian?

8) The Government proposes that: the National Data Guardian should have power to refer actions by an individual to the appropriate regulator for the profession concerned.

We agree with this proposal.

9) Please also provide any other comments on how the National Data Guardian might advise and challenge professionals working outside the regulated professions or organisations.

The National Data Guardian could advise on terms and conditions for inclusion in employment contracts for people who handle health and care data e.g. academic researchers who do not belong to a particular professional body.

10) Please also provide any other comments on how the National Data Guardian and regulators can maximise the appropriate use of existing sanctions and fines.

The government may wish to consider publishing a summary of any fines and sanctions issued in a publicly accessible forum (e.g. a website). This may act as a deterrent to organisations, but also help to reassure members of the public that actions have been taken to address inappropriate data sharing and/or breaches.

11) The Government is seeking views on the most suitable long-term location for the National Data Guardian.

We would argue that to maintain independence, this not be in the HSCIC or health service, akin to an ombudsman role.

12) The Government proposes that: the National Data Guardian's annual report should include a section demonstrating how the National Data Guardian has sought

and gathered the views of the public and how those views will inform work in the future.

We agree with this proposal.

13) The Government proposes that: The National Data Guardian, CAG and the HSCIC should agree and publish a Memorandum of Understanding that sets out the National Data Guardian remit in relation to the additional safeguards that are being put in place as described at paragraph 4.2.

Although we have no issue with publishing such a Memorandum, as it currently stands, the nature of the content is too broad for us to comment on meaningfully.

14) The Government proposes that: The National Data Guardian should engage with the relevant regulators of organisations outside the health and care system to ensure that they understand their obligations and responsibilities in relation to the health and care data to which they have access.

We agree with this proposal and think this is a highly important function of the role. The same standards should apply (and be seen to be applied) to organisations outside of the health service to inspire public confidence.

15) Do you have any comments or views on the potential impact that these proposals have on equality between different groups and health inequalities?

It is particularly important that organisations which hold health and social care data and work with populations with known health inequalities - especially smaller ones with limited resources - are not unduly obstructed by new procedures for accessing data, the activities of the data guardian or demonstration of compliance to their rules.

16) Do you have any comments or views on the potential impact that these proposals have on the potential for additional administrative and financial burdens?

Due consideration should be given to ensure these proposals are necessary, efficient and not unnecessarily bureaucratic.